

ORIGINAL ARTICLE

The Unmet Needs Among Parents of Disabled Children at Support Institutions in Kelantan, Malaysia

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ABSTRACT

Introduction: Parents of a disabled child might require extra basic needs which most of the time are unmet due to several factors. Thus, understanding the unmet needs could help the respective institution to provide and prioritise the needs required. **Methods:** A cross-sectional study was conducted between September to December 2013 to determine the proportion of unmet needs among parents of children with disabilities at support institutions in Kelantan, Malaysia. Biological parents of disabled children aged between 2 to 18 years old were included in the study. A 35-item validated Malay version of the Family Needs Survey was used in this study. A scoring of 4-point Likert scale was used; the prevalence of unmet needs was determined based on the proportion of those who scored "3" from each domain. **Results:** A total of 226 parents were involved in the present study. The mean age of parents and children were 44.6 (8.99) and 10.2 (4.85) years old respectively. The most common type of disabilities was learning disability (n=151, 66.8%). The unmet need for information has the highest prevalence (97.8%), followed by the unmet need for social support (93.8%). **Conclusion:** Parents with disabled children require information to guide them in managing their children. Findings from this study may better enable policymakers to devote resources in assisting parents, and service providers in designing appropriate interventions in fulfilling the unmet needs of these parents.

Keywords: Needs, Parents, Disabled children, Malaysia

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INTRODUCTION

It is estimated that 10% of the world population experience some form of disability. Of these, 150 to 250 million involved children (1). In Malaysia, the proportion of children with disability (CWD) ranged between 10% to 16% of the total number of children, and the rates vary according to the source of data (2). Regardless of the sources, statistics currently show an increasing trend in the number of newly-registered CWD (2, 3). As for the Kelantan population, the number increased from 27,554 in 2010 to 38,383 in 2012 (4). Development of new technologies is considered as one of the factors that contribute to the identification of the disabilities that give rise in the proportion (5).

Parental care for a CWD is an enormous responsibility, which far exceeds the typical parental care as most

CWD need long-term care due to their limitation (6). Looking after CWD is a massive challenge to parents as they need to balance their life priorities (7). The parents often require extraordinary physical, emotional, social and financial support in taking care of the CWD. Besides taking care of the physical need of the child, parents must also coordinate with other requirements such as numerous and multifaceted medical treatment, education and developmental interventions related to the disabilities, apart from fulfilling the needs of other family members.

In taking care for CWD, parents experience the need for information, social and financial support, community services and a range of services (8-10). Limitations possessed by the children due to the disabilities become reasons for the parents to experience unmet needs. Disability causes these families to have additional needs compared to those without CWD (11). The extra task includes assistance in the physically disabled child in his or her daily living activity such as dressing, feeding and walking.

As for children with learning disability, the parents need to focus more on their schooling activities because of the difficulties in understanding words, following commands, socialising or even behavioural problem (12). However, little is known about the status of various unmet needs among parents who had CWD in Malaysia; particularly in Kelantan where the majority of the populations were from the low socioeconomic background. Hence, the present study was conducted to determine the proportion of unmet needs among parents of children with disabilities at support institutions in Kelantan, Malaysia.

MATERIALS AND METHODS

Study Design and Location

The current study applied a cross-sectional design involving government and non-governmental support institutions in Kelantan, Malaysia with the majority of its population are Malays. There are eleven districts in the state, and each district has at least one Community-based Rehabilitation Centre (CRC). The CRC is operated under the Department of Social Welfare, a governmental institution under the Ministry of Women, Family and Community Development. Apart from these CRCs, there are other non-governmental organisations (NGO) that are directly involved in the management of disabled people like Yayasan Orang Kurang Upaya Kelantan (YOKUK), Pusat Asuhan Kanak-Kanak Spastik (PUSAKAS) and Kristal. The institutions chosen for the present study were CRC, YOKUK, PUSAKAS and Kristal. The institutions were purposely selected based on the availability of the study participants.

Study Population and Sampling method

This study involved parents with disabled children. They were recruited from the above institutions. The number of samples was calculated based on the objective of the study which was to determine the proportion of the unmet need among parent living with disabled children. The formula used was a single proportion formula. Using the proportion reported by Suriati et al. (2011) (9), the required sample was 207. After considering 10% of the non-response rate, the number of samples required to achieve the objective was 228.

To ensure the representativeness of the sample, the districts were randomly selected. Five districts; Kota Bharu, Machang, Bachok, Pasir Mas and Tumpat districts were chosen using simple random sampling methods. All CRCs located in the chosen districts [Kota Bharu (5), Machang (4), Bachok (2), Pasir Mas (3) and Tumpat (6)] were included in the study. Due to the limited number of NGOs in Kelantan, Malaysia, all three institutions were included in the study. Since the number of CRCs exceeded the number of NGOs, a proportionate sampling method was applied to obtain the number of parents. The lists of parents were obtained from the institution, and they were systematically randomly selected. Eighty

percent of the parents were recruited from CRCs and the rest from the NGOs. Biological parents whose disabled child aged between 2 to 18 years old were included in the present study. A parent who is more dominant in taking care of the child was chosen to be included in the present study.

Research tool

A proforma and the guided validated Malay version Family Needs Survey (FNS) questionnaire were used in the present study. The FNS questionnaire has an excellent internal consistency with the overall Cronbach's alpha of 0.91, with subscales ranging from 0.74 to 0.88 with a good face- and content- validity (9). In the present study, a similar excellent internal consistency reliability with the overall Cronbach's alpha of 0.90 was detected.

The FNS questionnaire has 35 items and composed of six domains which included the need for information, the need for social support, community services, explaining to others, financial support and family function. It applies a 4-point Likert scale ranging from 0 to 3 whereby "0" implies not applicable and "3" indicated the respondent need help with the statement issue. To fulfil the objective of the current study, the proportion of each reported unmet need was determined by summing up the frequency of those who gave score "3" from the item of each domain.

In the present study, low socioeconomic status was defined as those with a household income of RM1000 per month or less. Meanwhile, those with household income more than RM1000 was considered high socioeconomic status. This classification was based on the poverty line index set by the Malaysian Economic Planning Unit (13).

Data Analyses

Data were entered and analysed using SPSS version 20.0. The descriptive analysis was used to describe the socio-demographic characteristics of the parents. The numerical variables were presented using mean and standard deviation (SD) and the categorical variable was presented using frequency and percentage. The score was entered and labelled as those who scored "0" till "2" as 0 which means their need is met for the item mentioned in the domain, while those who scored "3" was labelled as 1 which means the item is still unmet.

The proportion of the unmet needs of each domain was determined by calculating the proportion of respondent who gave score "3" at least for one item from the domain. The proportion of unmet need of each item was determined by summing up those who scored "3" of that item over the number of total respondents.

Ethical approval

The approval to conduct the study was obtained from the Human Ethics Committee of Universiti Sains Malaysia

dated 25th March 2013 (Ref no: USMKK/PPP/JEPem [261.3.(1)]) and from all the support institutions. The consent from each respondent was obtained before the start of the study. Confidentiality is warranted to observe rights for privacy and confidentiality.

RESULTS

A total of 226 parents were involved in the current study. The response rate was 99.1%. Majority of the parents were Malay (95.1%), mothers (72.1%), married (88.5%), had a low educational background (89.8%) and low socioeconomic status (83.6%) (Table I). The mean (SD) age of children with disability was 10.2 (4.85) year old and 125 (55.3%) of them were boys. Majority of them had a learning disability (66.8%) (Table II).

Out of six domains, the unmet need for information had the highest rating (97.8%). It is followed by the unmet need for social support (93.8%), the unmet need for community services (90.3%), the unmet need for financial support (82.7%), the unmet need for family functioning (67.7%) and the unmet need to explain to others (57.5%) (Figure 1).

Further analysis shows that majority of parents reported the unmet need of information about the health and

Table I: Socio-demographic characteristics of the parents (n=226)

Parameters	Mean (SD)	n (%)
Age (year)	44.6 (8.99)	
Father		63 (27.9)
Mother		163 (72.1)
Race		
Malay		215 (95.1)
Non-Malay		11 (4.9)
Marriage status		
Married		200 (88.5)
Divorcee		26 (11.5)
Education level		
Low		203(89.8)
High		23 (10.2)
Distance [house to institute] (km)	6.3 (6.29)	
Socioeconomic Status		
Low		189 (83.6)
High		37 (16.4)
Number of children in the family	4 (3)*	
Has own transport		
Yes		194 (85.8)
No		32 (14.2)
Presence of Chronic disease		
Yes		32 (14.2)
No		194 (85.8)

* Median (IQR)

Table II: Characteristics of the children involved in the study (n=226)

Parameters	Mean (SD)	n (%)
Age (year)	10.2 (4.85)	
Sex		
Male		125 (55.3)
Female		101 (44.7)
Race		
Malay		215 (95.1)
Non-Malay		11 (4.9)
Type of disability		
Learning problem		151 (66.8)
Physical		46 (20.4)
Multiple		29 (12.8)
Age at diagnosis (year)	1.8 (2.80)	
Presence of medical problem		
Yes		40 (17.7)
No		186 (82.3)
Requires follow-up		
Yes		143 (63.3)
No		83 (36.7)
Register with JKM		
Yes		216 (95.6)
No		10 (4.4)

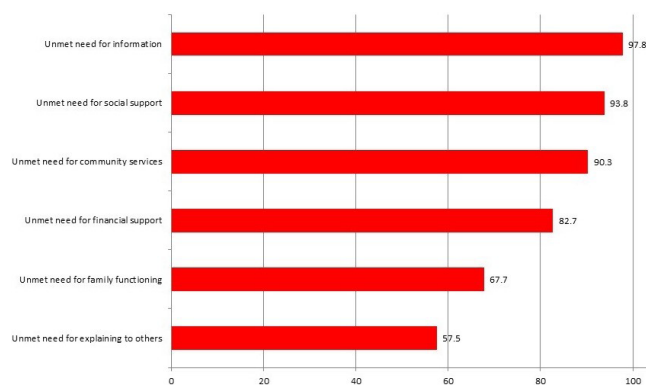


Figure 1: The proportion of unmet needs by domain reported by parents (n = 226)

related services that they might need when the child gets older, followed by information on teaching methods for the special child and developmental milestone of a disabled child. As for the need for social support, most parents reported that they need more time to talk to the teachers or therapists and more opportunities to speak to parents with similar problems. The parents also reported the need for community care; in particular, finding dental services for a disabled child and a doctor who understands the need of the child. Looking into the need for financial support, most of them agreed that they needed money to pay for basic expenses and specialized equipment for the child (Table III).

DISCUSSION

In general, the characteristics of parents of CWD in the

Table III: The proportion of unmet needs according to items reported by parents (n=226)

Type of need	n (%)
INFORMATION	
Information about my child's condition or disability	182 (80.5)
Information about how to handle my child's behaviour	180 (79.6)
Information about how to teach my child	201 (88.9)
Information on how to play with or talk to my child	179 (79.2)
Information on the services that are presently available	175 (77.4)
Information about the services my child might receive in the future	206 (92.5)
Information about how children grow and develop	191 (84.5)
SOCIAL SUPPORT	
Someone in my family that I can talk to more about problems	141 (62.4)
More friends that I can talk to	123 (54.4)
More opportunities to meet and talk with other parents	151 (66.8)
More time to talk with my child's teacher or therapist	164 (72.6)
Meet more regularly with a counsellor (psychologist, social worker, psychiatrist)	105 (46.5)
Talk more to a religious person who could help me deal with problems	101 (44.7)
Reading material about other parents who have a child similar to mine	147 (65.0)
More time for myself	85 (37.6)
EXPLAINING TO OTHERS	
How to explain my child's condition to his or her siblings	94 (41.6)
Explaining my child's condition to either my spouse or my spouse's parents	72 (31.9)
My spouse needs help in understanding our child's condition	68 (30.1)
How to respond when others ask about my child's condition	87 (38.5)
Explaining my child's condition to other children	81 (35.8)
COMMUNITY SERVICES	
Locating a doctor who understands my child's need	157 (69.5)
Locating a dentist who will see my child	172 (76.1)
Locating babysitters who are willing and able to care for my child	55 (24.3)
Locating a preschool for my child	145 (64.2)
Getting appropriate care for my child during religious activity	88 (38.9)
FINANCIAL SUPPORT	
Paying for expenses such as food	157 (69.5)
Getting special equipment for my child's needs	135 (59.7)
Paying for therapy, daycare, or other services my child needs	101 (44.7)
More counselling or help in getting a job	58 (25.7)
Paying for babysitting or respite care	59 (26.1)
Paying for toys that my child needs	87 (38.5)
FAMILY FUNCTIONING	
Discussing problems and reaching solutions	105 (46.5)
Learning how to support each other during difficult times	118 (52.2)
Deciding who will do household chores, child care, and other family tasks	69 (30.5)
Deciding on and doing recreational activities	93 (41.2)

current study were relatively homogenous. The mean age of the parents was approximately 45 years old. Their emotional and physical strength is essential in ensuring proper care for the family, especially when having a child with disabilities. Similarly, other studies reported that the mean age of caregivers who participated in their studies was in the mid-40s (6, 14). Almost all of them were Malays (95.1%) which represent the major ethnic in Kelantan, Malaysia (13) and female because mothers are the primary caregiver in a typical household. A similar observation was found in other studies as the mother is more dominant in looking after the child and is more willing to participate in the previous studies (6, 9, 14). Often, mothers spend more time raising and taking care of disabled children, rather than the fathers who typically work outside.

Out of six domains queried in the FNS questionnaire, the need for information had the highest rating, followed by the need for social support, the need for community services, the need for financial aid and last but not least the need for explaining to others. These findings were almost similar to a study conducted by Suriati et al. among parents visiting CRC in Selangor (9). Parallel discoveries were reported by many studies across the globe. Most parents reported the need for information as the most common unmet needs in taking care of their CWD (15-19). However other studies claimed respite care (20) and educational provision as the greatest unmet need among caregivers of CWD (21). In explaining the finding of this study, it was observed that most parents came from a low socio-economic background and were rarely exposed to the information required in the proper care of CWD. Hence, possibly they assumed the need for such information is crucial and should be met accordingly. It was also postulated from the literature that the need for information might stem from the expectation of the mothers, lack of support, the role of healthcare professionals in providing care (22) and low functional dependence of the child (23).

In exploring the needs of the information required, most parents reported that the unmet need for information is related to the services needed for their children in the future. This is consistent with their aspirations of sending their children to special schools when the child is older. The information is much needed to secure the future of the children and to make the necessary preparation and planning for the worse. Other studies also reported the same finding (8, 9). It showed that issues related to the future management of CWD is extremely important as the child gets older and thus requiring more individual attention and supervision.

Additionally, parents also expressed family needs for information in locating community activities (24). Looking for appropriate and feasible services for older children is not an easy task. It is even more complicated and difficult for parents with low socioeconomic status.

They worry about the future of their child and how the child will cope with the surrounding environment when they are no longer able to care for them (16, 25).

Besides the need for information, the second highest unmet need reported by the parents was the need for social support. They needed more time to build a good relationship with the teacher or therapist who teaches or treat the child. This is very important because all the information provided by the school or the physiotherapists will be practised at home. Thus, the process can be continued and does not end at school or physiotherapy unit. Apart from that, they also require more opportunities to meet and talk with other parents who faced a similar problem. Sharing information on difficulties in managing children with the same disabilities are very useful and can be a stress-reliever. Shared information may help parents to improve their child's condition. Parents support group are the best channel for sharing experiences and gain benefit from each other (10). The group not only gives physical support but more importantly, provide inner and emotional support for parents to be stronger in facing the challenges.

The parents also expressed the unmet need for community support in locating doctors and dentists who can provide services for their disabled children. There are many doctors and dentist in the community that treat normal individuals, but very few provide the services for a disabled child. This is consistent with the findings of a study that showed the lack of medical and dental services being reported by a large number of parents with CWD (26). This might be due to an insufficient number of professionals who specialise in treating a specific group of patients globally (1, 26) and specifically in Malaysia (2, 22). Consequently, the services offered to the CWD and their families were inadequate, and they were often left out.

The unmet need for financial support is one of the essential concerns. Majority of the parents faced financial difficulty in paying for their child's expenses. These include expenses to buy special formula milk, food, equipment or devices and payment for specialized services needed by their child. Other studies also reported that managing CWD carries a significant financial burden over time (11, 16). As a result, the socioeconomic background has been identified as one of the factors leading to various unmet needs especially among the poor (27-30). In the current study, four-fifth of the parents earned less than RM1000 per month. These group of parents needed more financial support than others. Even though the majority of parents were registered with Department of Social Welfare and received a special allowance (RM150 per disabled child) (31), yet the amount of money given was insufficient to fulfil even the basic requirement for CWD.

The least reported unmet need among the parents was the need for family functioning and explaining to others. Few studies reported the same pattern of finding (8, 9). Despite the low prevalence of this unmet need, a good family support system continues to be one of the critical factors in maintaining the function. Parents reported some degree of difficulty to explain the condition of the child to other siblings or close relatives. The condition could be due to the lack of knowledge of parents and their fear of misjudgement by other siblings towards the disabled child (32). However, this element is also important because normal children could influence the growth and development of CWD. Thus, parents need to assess the entire problem carefully and discuss the problem related to CWD openly with other siblings. Indeed, this relationship will make up a child's first social network and becoming the basis for his or her interactions with other people outside the family (32).

There are some limitations to the current study that may limit the generalisation of the findings. In this study, the unmet need was determined from the parent report of perceived need. Their perceived need is subject to both recognition and recall bias. The unmet needs assessed may be restricted to those that the family is able or willing to identify and this study was based on perceptions that may change over time. This study measured unmet needs among parents of CWD at the support institutions at only one point in time. Therefore, the causal direction of the predictive factors between the unmet needs of the parents and characteristics of the parents and children is difficult to determine. In other words, since this study design is cross-sectional, a causal association cannot be demonstrated.

CONCLUSION

The current study shows that the need for information related to future services for disabled children and the overall development of the child is a major concern by the parents. Similarly, the unmet needs for financial and social support is a potential stressor that should not be underestimated. Future service planning is required to overcome unmet needs that may stem from inadequate service provision.

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